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Title: The nature and extent of service user involvement in critical care research and quality improvement; a scoping review of the literature

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Abstract

The importance of involving patients and the public in health care research is globally recognised, but how best to do this in critical care is unclear. The aim of this first published review was to explore the extent and nature of evidence on service user involvement in critical care research and quality improvement. Using the scoping review framework described by Arksey & O'Malley (2005) a team of service user and critical care researchers searched eleven online databases, reviewed relevant websites, conducted forward and backward citation searching and contacted subject experts. Extracted data were subjected to a narrative synthesis based on the objectives of the review.

Findings from a broad range of evidence support that involvement is becoming more commonplace and that experiences are generally positive. Data extracted from 34 publications identify that involvement is most commonly reported at the level of consultation or participation in project teams, however, the extent to which involvement impacts on projects output remains unclear. Key barriers and facilitators relate to the challenge of recruiting a diverse group of service users, dealing with power hierarchies, being adaptable and effective consideration of the resource requirements. More research is required to identify the most effective methods to support the opportunity for involvement and more thorough reporting of service user involvement practices is strongly recommended.

Keywords

Patient and public involvement; Health research; Critical Care; Consumer; Improvement science

1.0 Introduction

Patient and public involvement (PPI) in healthcare is strongly endorsed by the National Institute for Health Research (NIHR) in England (Denegri, 2015) and is a common pre-requisite for obtaining funding in the United Kingdom (UK), across Europe and Worldwide (Petit & Locock, 2013). There is a growing acceptance that health research and quality improvement (QI) work benefits from the personal insights and experiential knowledge of service users; that people have a right to be involved in work that may impact on their health or the services they receive, and that PPI helps improve the quality, relevance and impact of projects. (Beresford, 2005; Boote et al., 2011; Thompson et al., 2009). Implementation science literature also highlights the importance of engaging all stakeholders for successful knowledge transfer and service improvement (Ogden & Fixsen, 2014; Boaz et al., 2016). However, although PPI in both research and QI has expanded considerably in recent years, there remains an insufficient understanding of the most effective ways of doing it or the difference it makes to improving the health service (Nilsen et al., 2006; Petit & Locock, 2013; Staniszewska et al., 2008; Staniszewska et al., 2013).

Describing three levels of involvement (Table 1), the NIHR funded body that promotes public involvement in England (INVOLVE), defines PPI as projects carried out '*with*' or '*by*' members of the public rather than '*to*', '*about*' or '*for*' them (Denegri, 2015). Within critical care, PPI usually refers to the involvement of former patients and their family members, who are described as service users.

Table 1: Levels of public and patient involvement (Denegri, 2015)

Previous reviews have focused on PPI related to patient safety initiatives (The Health Foundation, 2013), health policy and commissioning (Conklin et al., 2012; Crawford et al., 2002), and the research process itself (Boote et al., 2012; Boote et al., 2015; Brett et al., 2014; Staley, 2009; Viswanathan et al., 2009) in a range of population groups, but the involvement of people who have experienced critical illness has not been specifically explored. Having a critical illness and being in an intensive care unit (ICU) frequently leaves the individual and their family with ongoing physical and/or psychosocial sequelae (Griffiths et al., 2013; NICE, 2009). Involving former ICU patients and their family members in research or QI can be challenging due to the chronic health problems patients experience after discharge from hospital and because ICUs often admit out of area patients for speciality care. Some minority groups can also be difficult to access or engage (Dawson et al., 2015).

The aim of this review was to synthesise current evidence around best practice for PPI within critical care. The primary research question was:

"*How have former ICU patients and their families been involved in critical care research and/or QI projects?"*

As advised by Armstrong et al. (2011) a series of sub-questions were additionally identified to enable a clearly articulated scope of enquiry:

1. *How has PPI been described; what terminology is used and how is it interpreted?*
2. *What levels of involvement have been described?*
3. *What is the impact of involving critical care service users?*
4. *What are the barriers and/or facilitators related to PPI in critical care?*

The review questions emerged from local work with critical care service users and service providers (Bench et al., 2012; Goulding et al., 2015; Bench et al., 2016). These experiences identified a current lack of understanding around how best to involve former patients and their families and concerns regarding the impact of not doing it right.

2.0 Method

Scoping reviews involve the narrative synthesis of a broad and diverse range of evidence, commonly supplemented with consultative, consensus-building methodologies (Arksey & O'Malley, 2005; Davis et al., 2006). They can help identify gaps in the existing evidence, determine whether or not further reviews are justified and have the potential to influence policy and practice developments (Arksey & O'Malley, 2005; Armstrong et al., 2011; Davis et al., 2006). This review followed the six-stage framework described by Arksey & O'Malley (2005) and was further informed by the recommendations of Levac et al., (2010), Armstrong et al. (2011) and Daudt et al. (2013).

2.1 The research team

King's Improvement Science (KIS), a Charity funded arm of the NIHR Collaboration for Leadership in Applied Health Research (CLAHRC), South London employed all members of the research team (SB, EE, KP). The team reflected a breadth of experiences and perspectives on PPI in health care research: EE and KP have mental health service user backgrounds and work as service user researchers and SB is a critical care nurse researcher with previous experience of PPI. A Professor of service user research (DR) provided additional support, and advice from two research librarians helped devise the search strategy.

2.2 Identifying relevant studies

Eleven online databases (CINAHL, MEDLINE, EMBASE, Psychinfo, Social Policy & Practice, Web of Science, British Nursing Index, ASSIA, Kings Fund, Scopus and EthoS) were searched using the same search terms and strings (Table 2). Each term was searched as a free text term and where available, 'MESH' or 'Major subject headings' were used. Truncation (e.g. *, $) was used where available to account for differing spellings of similar terms.

Table 2: Search terms and strings

The Boolean operator 'OR' was used to retrieve results from any of the synonyms within each string. Overall results from strings A-D were then combined in the following way: (A AND B) AND (C AND D). After the initial test, 'NOT E' was added to avoid studies investigating 'proton pump inhibitors' rather than 'public and patient involvement' appearing in the results for PPI. Finally, the limits of 'Human' and 'English Language' were applied. To maximise the chance of retrieving of all relevant evidence, no date limits were set.

A search of relevant organisational, professional and charity websites was also undertaken and past conference abstracts from critical care and PPI organisations were screened. The PPI leads for all 13 CLAHRCs in England and a number of

other experts identified through word of mouth were contacted by email. Reference lists of all retrieved citations were checked and the Google scholar platform used to complete a process of forward citation searching. For all publications limited to an abstract or other project summary, authors were contacted for more information. The transcripts of the resultant telephone conversations and email responses from those who responded were added to the dataset. Retrieved citations from all sources were managed in COVIDENCE, an online software platform run by Veritas Health Innovation.

2.3 Study selection

The final selection of studies was guided by predetermined inclusion and exclusion criteria (Table 3).

Table 3: Inclusion and exclusion criteria

A single researcher screened all titles (*n*=4654), with 10% of those marked for exclusion reviewed by a second person. All researchers reviewed the remaining 39 citations, 34 of which were included in the review. Disagreements were resolved using a consensus approach. A decision was taken to exclude protocols and focus instead on work that had already been conducted and written up in some form. Where a full text version of a study was available, additional published abstracts were also excluded. Figure I provides an overview of the search process.

Figure 1: Flowchart of search process

2.4 Data charting, collation and analysis

Data were extracted, collated on an EXCEL spreadsheet and cross checked by all three researchers. Using a predetermined framework, a deductive approach focused on extracting and synthesising data with reference to the study objectives. In accordance with scoping review practice, no quality assessment of studies was performed (Arksey & O'Malley, 2005). Data were synthesised narratively to summarise current knowledge and practice around the nature and extent of PPI in critical care and its potential impacts.

3.0 Results

The 34 papers included in the review were all published in the period 2003-2016. There were 19 full text papers and 15 conference abstracts/project summaries, representing 29 QI or research projects (Table 4). Five papers reported work focused on a neonatal or paediatric, as opposed to an adult patient population. The majority of projects were conducted in the UK (*n*=18), however, seven papers reported work from the United States (US) and two reported data from a project conducted in Australia.

Table 4: Included papers

3.1 Study designs

Only two projects generated research data evaluating PPI approaches. Locock et al. (2014a) used ethnography to evaluate an Accelerated Experience Based Co-Design (AEBCD) project undertaken in two ICUs. Experience Based Co-Design is a six-stage process, which includes collating patient and staff experience data, followed by staff and service users working together to agree and develop QI priorities. The papers included in this review report an accelerated version of this process (AEBCD), using already available trigger films as an alternative to developing them during the project period. The ethnographic evaluation involved 155 hours of observations, 33 individual interviews and two group interviews with staff, patient and carer participants and facilitators. One hundred and sixty-six evaluation forms were also completed. Data were thematically analysed and a comparative framework developed based on key themes. Boaz et al. (2016) report data specific to the contribution of service users in identifying, designing and implementing quality improvement activities in the context of the AEBCD project and the discussion papers by Robert et al. (2015) and Tollyfield (2014) add further reflective information from the same AEBCD project regarding the PPI activities, their impact on project outcomes, and the barriers and facilitators associated with their use.

Trajkovski et al. (2015a; 2015b) also report evaluative data on their use of Appreciative Inquiry (AI) in a neonatal ICU. AI is a qualitative interpretative approach consisting of a 4D cycle: Discovery phase (appreciating and valuing what is best of what is or has been-strengths); Dream phase (envisioning 'what might be' or affirmative exploration); Design phase (co-constructing 'what should be' or the ideal); Destiny phase (sustaining what will be or envisioned future). Researchers initially observed a one-day workshop event. Data from the group discussions were audio recorded, interactions and processes observed and field notes kept. Data were synthesized using qualitative thematic analysis. Two years later, focus groups and interviews were conducted during the destiny phase of the project and data were subjected to a process of inductive thematic analysis (Trajkovski et al. 2015b).

The remaining papers included in this review detail how service users were involved in research studies or QI initiatives, with some reflections on how involvement impacted on project outcomes and experiences. These papers do not include any evaluative/research data. Findings from all publications are summarised under four overarching themes: types, degrees and extent of service user involvement; processes; impacts; barriers to and facilitators of PPI.

3.3 Types, degrees and extent of service user involvement

Data about the number of service users involved in projects, their demographic details or the extent of their involvement were generally poorly reported, with no detail provided in some cases (for example, Gooding et al., 2012).

The number of service users involved ranged from one to 181. Thirty-three former ICU patients and family members were included in the AEBCD project (Locock et al. 2014a) whereas the AI project by Trajkovski et al. (2015a; 2015b) only included eight family members in total. Most other projects included approximately six to eight people, most commonly as members of advisory groups.

A desire to involve people who were cognitively intact, had recent experiences and who lived locally was reported (Kingsbury, 2010; Menzies et al., 2011). Wilcock et al. (2003) describe how they attempted to "*sample patients at different points in their journey, but…* [not to] *actively seek to reproduce our local demographics*" (page 427). Similarly, Locock et al. (2014a) report seeking to include a range of people, although details of those who took part was limited to a statement that all "*were adults able to give informed consent…they or their relative had received care in one of the four participating services during the 6-month period of the fieldwork*" (page 12).

From the available details, adult men and women aged 23-87 years including former patients with varying degrees and types of illness and their family members (partners, children, siblings, parents, aunts) were reported to have taken part in included projects. There was also evidence of the involvement of children and young people, aged 8-16 years (Menzies et al., 2011; Menzies et al., 2014) and of bereaved family members (Menzies et al., 2011). Demographic details were very limited but typically reported white British middle class involvement (Higginson et al., 2013; Wilson et al., 2012) with zero-five years most commonly reported as the length of time since the ICU experience (Locock et al., 2014a; Reay et al., 2014; Trajkovski et al., 2015a; Trajkovski et al., 2015b; Willis et al., 2011). A number of people had been previously involved in charity work (Hamil & Heslop, 2010), volunteer roles (Anderson & Finley, 2010) or other research/QI initiatives.

Some authors referred to individuals involved as *former patients; family members; carers; relatives; parents; survivors*, whereas others used terms that more specifically described their involvement role, such as *service user representatives; patient advocates; surrogate decision makers; experts by experience; advisors; stakeholders; co-researchers*. The nature of involvement was also variably described using terms such as *collaboration; partnership; participation; co-design; co-production; engagement; input; involvement*. Different authors frequently used similar terms to indicate

different types of involvement. For example, Trajkowski et al. (2015b) describe parents and staff involved in their project as *co-researchers*, despite the study being designed and delivered by an academic research team. *Collaboration* was a term which appeared frequently, typically being used in the lay sense of the word by authors i.e. without a project meeting the INVOLVE definition (See Table 1), and sometimes used generally to describe a project in which some aspects would be considered consultation and others collaboration (Denegri, 2015).

Most publications described consultation activities (Table 5), where commonly service users' experience data informed the design of an intervention or service improvement initiative. There were also examples of collaboration, with service users named as co-authors or co-presenters, acting as service user representatives on project steering groups or helping to design or deliver solutions and/or interventions. Several studies seem to have utilised both consultation and collaboration processes and strategies (Table 5).

Table 5: Examples of consultation and collaboration

Findings from the ethnographic evaluation by Locock et al. (2014a) identify a variety of roles undertaken by patients and carers in their AEBCD study: sharing experiences, identifying priorities for quality improvement, co-developing potential solutions and helping to implement and evaluate agreed interventions. Other authors also report patient involvement in data collection and analysis (Table 5), but involvement in the early stages of designing projects or reviewing study documentation was rarely described.

3.4 Processes

In some cases, there was an attempt to follow standard research procedures to recruit people for involvement. For example, Goulding et al. (2015) describe how they approached patients during their critical care follow up clinic appointment. Locock et al. (2014a) also report using a purposive sampling technique. Darbyshire (2015b) used targeted adverts, placed on user group websites and in follow up clinics, to invite service users to become part of a research team. In other cases, patients and family members were contacted directly and invited to take part in a survey or interview or to be part of a departmental project. Alternatively, service user representatives were accessed via existing groups or via contacts from previous projects. In contrast, Hamil & Heslop (2010) report that the relative of a former patient involved in their QI work directly approached the unit offering to volunteer within the department.

3.4.1 Duration of involvement

For some service users, involvement was limited to a one-day event whereas for others, involvement lasted for two years or more. Locock et al. (2014a) report that, in their study, a few (*n*=3) patients remained actively involved after the AEBCD process had finished. Many of the publications based on service improvement also refer to ongoing relationships with service user representatives, particularly where advisory groups or 'collaboratives' were set up or where volunteer roles within the department were established.

3.4.2 Payment/incentives

Some project groups reported covering travel expenses and offering refreshments, whilst others provided incentives to compensate people for their time and participation. These included discounted or free services such as counselling and spa sessions, Christmas presents, gift certificates and crèche facilities. Only Ramsay (2013) reported offering a £50 payment, noting that this was often declined or given to charity. In some cases, involvement was reportedly viewed by service users as a way of paying back the health service for care received (Hamil & Heslop, 2010; Ramsay 2013; Wilson et al., 2012) and frequently described as including an element of therapeutic support for those involved.

3.5 Impacts

A wide range of service improvements was reported to have resulted from the QI projects (Table 6).

Table 6: Service improvement impacts

Boaz et al. (2016) note that patient involvement "*led to priorities and solutions that would not otherwise have occurred to frontline staff immersed in day-to-day service delivery*" (page 11). Service user involvement also led to the establishment of ongoing advisory/stakeholder /taskforce groups in a number of cases. For example, Trajkovski et al. (2015a) report the formation of a family centred care working party that met monthly.

Service user involvement was also reported to have impacted on research priorities (Reay et al., 2014) and on the design of a range of research based interventions and study methods. For example, Ramsay (2103) describes how a website designed as part of a wider research project was altered due to the involvement of service users stating *"One patient fell asleep when trying to read qualitative quotes on website, so web designers built in a function to enable it to be spoken rather than read. Also, one lady's husband was visually impaired, which led web designers to use different colours"* (telephone transcript). Darbyshire (2015b) explain that their research title and data collection plans were amended in light of service users' views and Menzies et al. (2014) report that PPI gave them a better understanding about how best to capture the perspectives of children with differing experiences.

3.5.1 Strengthened relationships

A key theme that emerged was the strengthened relationships that developed as a result of PPI. For example, Trajkovski et al. reflect on the partnership opportunities that arose from their aforementioned AI project, citing one parent who said *"This workshop is a good way of getting nurses and parents really working together"* (2015a, page 247) and another who said "*It has opened up amazing doors…we are now being invited to join other research projects and conferences…and this stems from the relationships we built*" (2015b, page 6).

Service user involvement was reported to have contributed to a change in culture, characterised by a greater sense of mutual respect between staff and service users (Trajkovski et al., 2015b). Darbyshire (2015a) states that, "*Having a 'real person' in the room can bring a sense of humanity to the research*" (page 2). Data further suggest that involvement increased service users' understanding of nurses' roles and actions (Trajkovski et al., 2015b), altered power dynamics (Menzies et al., 2011; Robert et al., 2015; Wilson et al., 2012) and helped uncover otherwise unexplored insights of relevance to patients and their families (Elliott et al., 2014). Williams et al. (2013) further reflect that the transactions that took place generated a "*social capital that creates and improves social provider-consumer networks"* (page 1).

3.5.2 Experiences of involvement

Experiences of involvement were generally described as positive and rewarding. Service users reported feeling listened to, having their views valued and feeling as though they were equal partners (Locock et al., 2014a; Trajkovski et al., 2015b; Menzies et al., 2011). Despite some initial concerns that involvement would lead to little or no change, service users noted that, "*It's great to see changes happening – it's not just lip service"* (Tollyfield, 2014, page 140). Service providers and researchers also reported positive experiences, with one staff member involved in an AEBCD project stating that, *"In twenty years of nursing I have never interacted with patients in this way before"* (Tollyfield, 2014, page 140).

Some initial feelings of apprehension about working together were reported, however, as project teams became more familiar with PPI, individuals reported feeling more comfortable and confident. Some service users also viewed the experience as a way of 'giving something back' (Locock et al., 2014a; Williams et al., 2013) with one patient saying "*I volunteer in the ICU as a token of gratitude and sincere thanks for being given another chance to carry on enjoying life, and to be able to continue giving a little back"* (Wilson et al., 2012, slide 11).

3.6 Barriers to and facilitators of involvement

Trying to recruit a 'representative' and diverse sample of service users was reported as challenging and rarely achieved. Willis et al. (2103) note that "*Several interested patients/families could not commit to the schedule request or could not travel the distance for the meetings… did not want to re-live their trauma experience* [or] *did not wish to participate in a group forum… Other potential members were excluded because they were discharged to extended care facilities or had transportation issues…had traumatic brain injuries and were not capable of communication* [foul language and inappropriate behaviour] *needs appropriate for this venue"* (page 87). Recruitment was reportedly most successful when people were approached via existing relationships (Bench et al., 2014; Ramsay, 2013). However, Darbyshire (2015b) reflects on the challenges their research team faced, trying to find people for every project and points out that, "*There seems to be a limited cohort of 'professional patients' within the ex-ICU patient community and they are at the point where they cannot take on more responsibilities*" (page 2).

The importance of involving people early and sustaining relationships was evident. However, this was not always possible or desired by service users. Locock et al. (2014a) report that patients ended their participation because they did not feel they had anything more to contribute or because they felt that implementation was not their responsibility. Some service users also became too ill to continue or found it too distressing to sustain involvement. Flexibility was considered vital, and being able to adapt to suit individual preferences and health status associated with more successful involvement (Boaz et al., 2016; Tollyfield, 2014).

Creating an environment in which people could work together as equals emerged as an important facilitator. Robert et al. (2015) discuss the potential for "*conflict and tension—often relating to issues of power...especially true if patients find it difficult to express their views because of a previous experience of very poor care...*" (page 2). Williams et al. (2013) report including equal numbers of providers and users as a means to avoiding power hierarchies. Differing priorities and levels of understanding between stakeholders also have to be addressed with sensitivity and openness. For example, Wilcock et al. (2003) point out that, *"feeding narratives back to interprofessional teams has to be handled carefully to avoid causing a defensive reaction to any implied criticism"* (page 428), whilst Trajkovski et al. (2015a) report providing reassurance to those involved that participation would "*have no effect on future associations with the health service*" (page 242).

Providing adequate time, space and support to work together was reported to be vital for successful PPI (Boaz et al., 2016; Wilson et al., 2012). One nurse involved in an AI project noted the importance of creating *"a physical and mental*

space that encouraged dialogue, built trust and created links between health professionals and parents" (Trajkovski et al., 2015b, page 4). A physical space suited to the purpose was reported as necessary. In their AI project, Trajkovski et al. (2015b) describe achieving this by using a location that was away from clinical ward distractions, easy to travel to and that offered free parking.

Organisational support emerged as a further facilitator of PPI. Tollyfield (2014) recommends that local staff be involved as much as possible and states that "*Buy-in from senior staff and the practice education team is absolutely necessary*" (page 137). Willis et al. (2013) also report the value of unit champions "*serving as the contact person for questions or concerns*" (page 87).

3.6.1 Training and resources

Providing sufficient time at the start of a project for service users to understand their role and to agree ground rules was described as important for success (Boaz et al., 2016). Ensuring adequate resources, such as costs associated with room hire, catering, parking and training are allocated for the duration of the project were also identified as facilitators of effective PPI (Dunn et al., 2006; Trajkovski et al., 2015b; Wilcock et al., 2003).

No reference was made to the provision of training for patients and family members. The need for staff training was highlighted in two projects (Locok et al., 2014a; Trajkovski et al., 2015b). There was, however, little evidence of such training, except in the papers by Locock et al. (2014a), where a half-day event for facilitators of their AEBCD project supplemented with email and telephone support from researchers was described.

4.0 Discussion

4.1 Types and levels of involvement

People become involved in critical care research and QI projects for many different reasons and take part in numerous different ways. Although descriptions of PPI used by authors did not always reflect the INVOLVE definitions (Denegri, 2015), we did not identify any examples of a user led/user controlled approach to PPI, a finding consistent with literature in the area of mental health where substantive and widespread service user/survivor leadership in research is discussed as something yet to be attained (Callard & Rose, 2010; Jones & Shattel, 2016).

Consultation was the main PPI approach described, predominantly using service users' experiences to inform service improvement. There is some evidence that involvement is growing in other areas-for example, participation in research

project steering groups. However, where collaboration was described in the reviewed papers, it appeared to be invariably initiated by health professionals or researchers.

Blurring of roles was also evident, with patients sometimes participating as research subjects as well as carrying out involvement activities, a finding also reported by Mathie et al. (2014). The impact of these combined roles and responsibilities on projects and individuals warrants future consideration.

4.2 Processes, methods and impact

The papers included in our review were predominantly descriptive, with very little evaluative/research data reported. There was also very limited information provided with regard to the service users involved, their experiences of PPI processes and outcomes or the facilitators and barriers associated with PPI in critical care service improvement and research projects. These findings concerning the paucity of detailed publically available information about PPI processes, methods and impact are consistent with those reported in generic literature on PPI (Barber et al., 2011; Conklin et al., 2012; Mathie et al., 2014; Mockford et al., 2012).

The absence of crucial information of this sort makes it difficult to fully understand and appreciate PPI processes and their likely impact (Conklin et al., 2012; Crawford et al., 2002; Nilsen et al., 2006). Findings from the present review do, however, support that PPI can influence the prioritisation of work streams, as well as the design of interventions and study methods. Data from our review also suggest that once people overcome their initial apprehension, service user involvement in critical care is associated with positive experiences.

4.3 Barriers to and facilitators of public and patient involvement

In agreement with the existing literature (Conklin et al., 2012; Staniszewska & Denegri 2013; Snape et al., 2014; Wilson et al., 2015), we found key facilitators associated with meaningful PPI to include availability of adequate time and resources/support for PPI activities; a physical and mental space conducive to collaborative working; organisational support and buy-in; flexibility and adaptability to suit different contexts, individual service user preferences and health needs; and creating a respectful environment in which people can work together in partnership. Findings also highlight the importance of making PPI routine, so that it becomes part of the organisational culture.

A key challenge reported in our review concerns the recruitment of ‘representative’ and diverse groups of service users to critical care research and QI projects. Service user ‘representativeness’ is a pervasive theme in the existing PPI-

related health research literature (Jones & Shattel, 2016; Mathie et al., 2014). Achieving a 'representative sample' of service users in the domain of PPI may be impossible and furthermore, may not be what we should be aiming for. No single person is able to represent others, thus we should perhaps be focusing more on how best we can capture the collective sharing of experiences, views and values among service users. Some authors also report a negativity and a tokenistic response towards involving service users, arguing that those involved tend to be articulate and able to work with project teams (El Enany et al., 2013). El Enany et al. (2013) argues that these service users are also complicit in professionalising their involvement role. However, what has been discussed in the literature as the 'professionalisation' of service users in PPI (Thompson et al., 2012) involves a complex set of issues. This entails a need to consider with greater care the social and material conditions underpinning the professionalisation of service users in the PPI arena.

How to access 'hard to reach' population groups, such as those from minority backgrounds, those who have been bereaved, or those who have cognitive difficulties is an unresolved dilemma. Findings from this review suggest a desire to include bereaved family members, but limited examples of this actually happening provides little evidence with which to guide future practice. It is often assumed that bereaved family members may not want to take part, but this remains an assumption rather than an informed understanding of their wishes and views. When it comes to former ICU patients who may experience cognitive difficulties, it should not be *a priori* assumed that this group of patients would not want or would not be able to be involved in research or QI initiatives; researchers and QI practitioners need to be more innovative, flexible and adaptable with regard to how people with cognitive difficulties can be involved, at whatever level they are able and want to.

4.4 Limitations of the review

Data about PPI is often hidden, is frequently not reflected in study titles or abstracts and may only be uncovered by word of mouth, making it difficult to identify using standard review processes (Rogers et al. 2016). This review included published abstracts as well as full text publications and no quality appraisal of included studies was undertaken. These decisions were taken because of the limited available research data and a desire to reflect the most current evidence status. We also excluded protocols as they do not necessarily reflect what actually happened. However, this can possibly mean that this review does not reflect fully the current state of PPI practice in critical care. Furthermore, studies in which service users were co-authors on the paper were in the minority, thus our findings are mostly reliant on professional reports of service users' views and experiences.

5.0 Conclusion

This is the first published review to detail the nature and extent of PPI in critical care research and QI. Limited research data were identified, but findings from a broad range of evidence support that PPI is becoming more commonplace. On the whole, we found experiences of PPI within critical care to be reported positively, and available data suggest that PPI does have a positive impact on both the design and conduct of both research and QI initiatives. The key barriers and facilitators of PPI that we identified relate to the challenge of recruiting a diverse group of service users, dealing with power hierarchies, being adaptable and effective consideration of the resource requirements. Findings lead us to the conclusion that we currently lack an evidence base with which to guide our practice. We offer the following recommendations and insights, which we hope will aid the future development of PPI in critical care in a systematic and evidence based way.

5.1 Policy, practice and research recommendations

PPI in critical care research/QI has received limited attention when it comes to the evaluation of its processes, methods and impact. More research is required to identify the best methods with which to recruit and involve people, as well as to explore the appropriateness of and timeliness for approaching and involving patient/family groups following hospital discharge.

Not being able to easily locate relevant literature is a significant barrier to the utilisation of available evidence. The development of a search filter for PPI, such as the one described in a study by Rogers et al. (2016) could aid the identification of literature on PPI in critical care, and its subsequent application to practice. However, as Rogers et al. (2016) acknowledge, locating PPI research hidden in the body of the text will remain an issue until database indexing and searching facilities are improved.

The lack of reporting regarding methods of PPI does not necessarily mean PPI did not take place, but it does mean that others are unable to learn from previous positive or negative experiences. Some toolkits and reporting guidelines for PPI activity are now available (Bagley et al., 2016; Staniszewska et al., 2011). Further development and application of these to critical care projects should help to address this important oversight, adding to the developing body of improvement science knowledge.

Finally, the papers included in our review raise a number of crucial implementation questions that future research needs to consider:

i) To what extent does PPI influence the adoption and implementation of QI programmes in critical care?

ii) How does PPI shape the complex environments (contexts) within which QI programmes in critical care are implemented?

iii) Does PPI impact on issues of fidelity to and adaptation of QI interventions in critical care, and if so, how?

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Tables

Table 1: Levels of Public and patient involvement (PPI) (Denegri, 2015)

Level	Definition
User-led/controlled	Actively driven, directed and managed (controlled) by service users and/or family members
Collaboration	Service users are actively and collaboratively involved as members of research or project implementation teams, as co-researchers, co-implementers and co-authors of academic publications
Consultation	Service users are consulted, asked for advice, and/or provide information that is used to inform decision making by others

Table 2: Search terms and strings

STRING A		STRING B	STRING C	STRING D	STRING E
Adjacent (5 words)					NOT
Service user(s)	Involv(e/s/d/ing/ment)	PPI	Critical illness	Research	Proton pump inhibitor
Patient(s)	Participat (e/es/ed/ion)	Coproduc (e/es/ed/tion)	Intensive care	Service evaluation(s)	
Famil(y/ies)	Inclu (de/des/ded/sion)	Co-creat(e/ed/tion)	Intensive therapy	Service improvement(s)	
Relative(s)	Engag (e/ing/ement/ed)		High dependency	Quality improvement	
Consumer(s)	Collaborat(e/es/ing/ed/ion)		ICU	QI	
Carer(s)	Partnership(s)		CCU	Analysis of healthcare	
Caregiver(s)	Cooperat (e/es/ed/tion)		HDU	Projects	
Public				Continuous improvement	

Table 3: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
All documents that report data about: • Any type of service user engagement or planned engagement in research, service development and/or clinical audit activities within critical care (adult, paediatric, obstetric and neonatal) • The nature, extent and terminology used to describe public and patient involvement PPI* • Methods for capturing PPI data and measurement • The impact of PPI on health or process outcomes • Impact of the research on individual users or research team members, on groups and/or on organisations • Experiences of and/or reflections on PPI	Documents that: • Only report service user satisfaction data, with no link to a service improvement/research initiative • Report data collected on projects conducted outside critical care • Do not report data collected/to be collected by the authors of the paper • Report study/quality improvement protocols

*PPI: Public and patient involvement

Table 4: Included papers

Project no.	Publications	Publication details	Country
1	Bench et al. (2012)	Describes development of a complex intervention for a MRC* guided research study.	United Kingdom
	Bench et al. (2014)	Reports evaluative data of discharge summaries co-designed during a MRC* study.	
2	Boaz et al. (2016)	Reflective paper drawing on data from an ethnographic evaluation of AEBCD**	United Kingdom
	Locock et al.(2014a)	Reports an ethnographic evaluation of AEBCD in two intensive care units.	
	Robert et al. (2015)	Reports experiences of using EBCD in intensive care.	

	Tollyfield (2014)	Reports a reflective account based on facilitating an AEBCD project.	
3	Carson et al. (2012)	Describes the development and evaluation of an information brochure for families of chronically critically ill patients.	United States
4	Dunn et al. (2006)	Reports the development of a web-based family centered care map in a neonatal intensive care unit.	United States
5	Elliott et al. (2014)	Summarises outcomes from a national stakeholder meeting to identify ways to improve outcomes for patients and families following critical illness.	United States
6	Gooding et al. (2012)	Describes the use of family and patient experiences to inform service improvements.	United States
7	Goulding et al. (2015)	Reports the findings of a quality improvement project to improve the quality of medical discharge summaries.	United Kingdom
8	Higginson et al. (2013)	Reports a MRC* guided study, which developed and evaluated a complex intervention around end of life care.	United Kingdom
9	Paul et al. (2004)	Reports an action research project, which developed and evaluated a transfer information booklet.	United Kingdom
10	Ramsay et al. (2014)	Reports the development of a complex intervention for critical illness rehabilitation using the MRC (2008) framework.	United Kingdom
11	Reay et al. (2014)	Reports on a national critical care research priority setting exercise.	UK United Kingdom
12	Trajkovski et al. (2015a) Trajkovski et al. (2015b)	Reports qualitative research, evaluating the use of Appreciative Inquiry to improve family centred care in a neonatal intensive care unit.	Australia
13	Wilcock et al. (2003)	Reports the results of a National Health Service modernization agency quality improvement initiative in critical care.	United Kingdom
14	Willis et al. (2013)	Describes the set-up of a patient and family advisory council in a trauma centre.	United States
	Abstracts	**Abstract details**	**Country**
15	Anderson & Finley (2010)[†]	Reports a local initiative to set up a patient and user group to inform quality improvement.	United Kingdom
16	Burgess & Hayes (2012)	Reports the development of a DVD of a patient's story and its use to facilitate dialogue with health care professionals.	United Kingdom
17	Darbyshire (2015a)	Reports the use of AEBCD to address noise issues.	United Kingdom
18	Darbyshire (2015b)	Reports findings from a focus group of former patients to aid the design of a study around recovery.	United Kingdom
19	Hamil & Heslop (2010)[†]	Reports the introduction of a volunteer role to support quality improvement.	United Kingdom
20	Haslett et al. (2009)	Reports a project exploring the opinions of family members to highlight elements of good practice and areas for improvement.	Unknown
21	Kingsbury (2010)[†]	Reports the re-development of an intensive care unit using information from patients/families collected through patient experience data.	Australia
22	Landon et al. (2014)	Reports the evaluation of regularly scheduled multidisciplinary meetings and a patient navigator.	United States
23	Meadows et al. (2010)[†]	Reports a co-production initiative to design service improvements on an adult cardiothoracic intensive care unit	United Kingdom
24	Menzies et al. (2011)[†]	Reports a focus group study with parents of former intensive care unit children, to inform clinical trial designs and a young persons' service user group used to advise on study materials.	United Kingdom
25	Menzies et al. (2014)[†]	Reports a consumer consultation activity to determine stakeholders and methods to communicate with them.	United Kingdom
26	Nasenbeny et al.(2014)	Details a service innovation project, which set up a patient and family advisory council to help lead quality improvement.	United States
27	Ramsay (2013)[†]	Details the development of a website designed in consultation with former patients/family members.	United Kingdom
29	Williams et al. (2013)[†]	Reports a co-production initiative to design service improvements for adults undergoing Extra Corporeal Membrane Oxygenation	United Kingdom

		therapy	
28	Wilson et al. (2012)[†]	Reports details of a nurse who interviewed patients about their experiences and the resultant activities.	United Kingdom

*Medical Research Council **Accelerated Experience-Based Co-Design [†] Author provided additional data

Table 5: Examples of consultation and collaboration

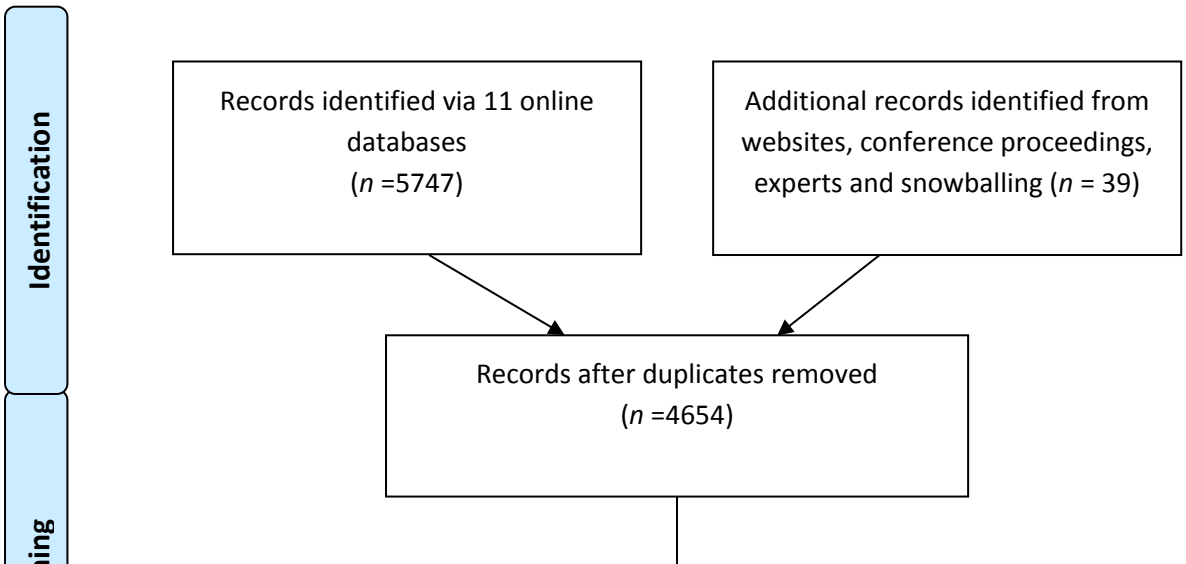
Consultation
• Advisory groups (four reports)
• Service user experiences/narratives informed intervention design or service improvement work (19 reports)
• Service users consulted on study design and/or asked to review study documents (six reports)
• Service users took part in stakeholder engagement activities such as workshops/research priority setting exercises (three reports)
Collaboration
• Service users on project steering group (nine reports)
• Service users participated in workshops or other activities focused on co-designing/co-producing a project, intervention, solution or implementation strategy (16 reports)
• Service users manage an area of service provision e.g. memorial service, care navigators, patient and family support roles, writing patient information, sourcing new equipment, teaching staff, chairing committees, representing service users on various committees, writing reports or other volunteer roles (seven reports)
• Service user assisted with data collection and/or data analysis (six reports)
• Service user co-authored publications/presentations or took part in other dissemination activities (five reports)

Table 6: Service improvement impacts

Publication	**Service improvements**
Boaz et al. (2016) Locock et al. (2014a) Tollyfield (2014) Robert et al.(2015)	• Sign to enhance dignity and privacy • Promotion of family involvement in personal care • Washing of patients' hair more regularly • Changing time of patient washes • Trial of a new wash basins • Encouraging wards to send patients' wash bags to the intensive care unit • Clocks to aid patient orientation • Encouraging nurses to brush patients' teeth more regularly • New toothbrushes • Promoting correct application of continuous positive airway pressure masks • Booklet informing patients about potential for hallucinations • Changing waste removal to outside of the rest period • Redesign of the intensive care unit discharge summary form • Redesigned lighting systems • Tablet computer applications to assist ventilated patients communicate • V-shaped pillows for postoperative patients • New process for transfer of patients' belongings from theatre to recovery ward • Improved patient-doctor communication during ward rounds
Bench et al. (2012; 2014)	• Intensive care unit discharge summaries for patients • Discharge information for patients and relatives

Higginson et al. (2013)	• End of life care communication strategy
Paul et al. (2004)	• Provision of discharge information
Trajkovski et al. (2015a; 2015b)	• New vision statement for display in the department • Updated information displayed on liquid-crystal display slides in between infant bed spaces for parents and sibling packs
Wilcock et al. (2003)	• Signs clearly stating the location of the hospital • Communication boards used by patients who are unable to talk during recovery reviewed and redeveloped. • Introduction of nurses visiting all preoperative patients, identifying particular needs and talking to them about the critical- care environment • Introduction of nurses explaining to patients who were due to be moved, the reasons and what to expect.
Willis et al. (2013)	• New whiteboards purchased and professionally customized • Journal with information from service users about their trauma experience • Communication book • Handout for trauma patients listing signs and symptoms of post traumatic stress and directions for seeking help
Gooding et al. (2012)	• Introduction of a way-finding improvement initiative • Introduction of a quiet initiative: quiet times; decibel monitoring; dimming lights; modification to linen and food carts wheels; soft pad doors; reducing ringing phones; night mode on intercom
Elliott et al. (2014)	• Brochure on leaving the intensive care unit modified to include a checklist of questions to identify when symptoms should be reported to the General Practitioner
Anderson & Finley (2010)	• Memorial service for bereaved families • Shorter patient information leaflets written in lay language • Bi-annual patient conference
Darbyshire (2015a)	• New noise policy
Hamil & Heslop (2010)	• Installation of a water cooler • Development of a medical information folder • Redecoration of waiting room • Televisions in overnight rooms
Haslett et al. (2009)	• Changes to practice addressing high noise levels, high levels of anxiety regarding discharge and difficulty identifying staff members' roles
Kingsbury (2010)	• Privacy included as an essential principle during the design of a new unit
Landon et al. (2014)	• Patient care navigator role introduced
Williams et al. (2013)	• Discharge summaries for patients, families, referring hospitals and General Practitioners
Nasenbeny et al. (2014)	• Intensive care unit liaison programme • End of life education for staff co-provided by service users

Figure 1: Flowchart of search process (adapted from Moher et al. 2009)



List of abbreviations used in manuscript

Accelerated Experience Based Co-Design (AEBCD)

Appreciative Inquiry (AI)

Collaboration for Leadership in Applied Health Research (CLAHRC)

Intensive care unit (ICU)

King's Improvement Science (KIS)

Medical Research Council (MRC)

National Institute for Health Research (NIHR)

Patient and public involvement (PPI)

Quality improvement (QI)

United Kingdom (UK)

United States (US)

PRISMA checklist [adapted by authors for use with scoping review methodology]

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a scoping review	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5-6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5-6
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in review)	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7-8
Data items	11	List and define all variables for which data were sought.	7-8

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies and how this information is to be used in any data synthesis.	8
Summary measures	13	State the principal summary measures	8
Synthesis of results	14	Describe the methods of handling data and combining results of studies	8
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	20
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7-8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	8-14
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	14-17
FUNDING			

Funding	27	Describe sources of funding for the review and other support (e.g., supply of data)	2